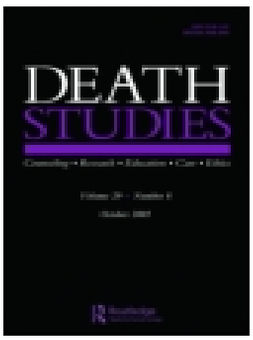

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Perinatal loss and parental loneliness: Narratives of late termination of pregnancy

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ABSTRACT

Advances in perinatal medicine, present increasing numbers of women with difficult decisions about their pregnancy. We explored the views of 5 parents and 5 perinatal healthcare professionals regarding late termination of pregnancy following the principles of qualitative content analysis. Parents deciding on whether to (dis)continue pregnancy needed more time and decisional support. Decentralized care and lacking continuity between caregivers led to negative experiences. No standardized bereavement services were offered after leaving the hospital. Integrating principles of perinatal palliative care to care might help to offer further decisional support and to overcome the fragmentation of care.

Advancing technologies in antenatal diagnostics and perinatal medicine place increasing numbers of pregnant women and their partners in situations where they must make difficult decisions about the outcomes of pregnancy. Fetal anomalies are normally confirmed in the second trimester of pregnancy (around 13–27 weeks of pregnancy). In cases where fetal anomalies raise doubts about the future wellbeing of the child, expecting parents might seek to re-confirm the test results, request a second opinion and/or further genetic testing with perinatal healthcare specialists. Nonetheless, depending on the social-legal circumstances at this stage of pregnancy, some expecting parents must make rapid decisions on terminating or continuing the pregnancy (Jones et al., 2017).

The safe provision of abortion has taken grounds worldwide since the beginning of the 21st century, but international legal regulations still vary (Singh et al., 2018). Since 2002, abortion (≤12 weeks of pregnancy) has been legalized in Switzerland if it is at the written request of the pregnant woman. Switzerland has one of the lowest abortion rates with 7.1 per 1000 women. Most abortions take place ≤12th week of pregnancy (95%) (BFS, 2019). In contrast to other countries, the Swiss Criminal Code stipulates that beyond the limit of ≤12 weeks of pregnancy, late termination of pregnancy (LTOP)[1] is exempt from penalty if a healthcare professional (HCP) confirms that the pregnancy is a threat to the woman's physical or mental health. No upper gestational age limit for LTOP is defined; however, Swiss law does require that the risk to the mother must increase as the gestational age of the fetus advances. Thus, LTOP by medically inducing labor or by a feticide[2] around or beyond the viability limit (at around 24 completed weeks of gestation) is practiced in Switzerland (T. M. Berger et al., 2011; NEK, 2018; Schweizerisches Strafgesetzbuch, 2002). Currently, approximately 1% of abortions rates are LTOPs at ≥20 weeks (BFS, 2019; NEK, 2018), and, although rare, they are expected to increase with advances in antenatal diagnostics, fetal imaging, access to genetic screening, and, in turn, diagnoses of fetal anomalies.

The decision to discontinue a pregnancy at ≥20 weeks poses unique ethical challenges to affected women, their partners as well as involved HCPs with obstetricians and midwives playing a major role (DiMiceli-Zsigmond et al., 2015). In these challenging situations obstetric HCPs must support decisions about life and death and respect the rights and values, and preferences of the mother, the father, and the fetus (Fleming et al., 2018; Oelhafen et al., 2019).

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Other perinatal specialists such as geneticists, neonatologists, palliative care providers, spiritual care givers, and psychiatrists often serve as supportive experts during antenatal consultations with prospective parents (Denney-Koelsch & Côté-Arsenault, 2020). So far, little is known about the practice of LTOPs at ≥20 weeks in Switzerland, which varies from institution to institution (Berger et al., 2020; NEK, 2018). In general, LTOPs are performed in university hospitals. 24% of Swiss clinics perform an abortion only up to 12 weeks of pregnancy, 33% perform abortion and/or LTOP up to 24 weeks, and 20% of clinics LTOP beyond 24 weeks (Rey & Seidenberg, 2010). Although beyond the scope of this article, it is important to note that it is not clear how often feticides occur in Switzerland. To date, no official figures exist since feticides are not recorded statistically (NEK, 2018).

Despite growing societal acceptance of abortion, the practice of LTOP has remained deeply stigmatized with women reporting social or self-judgment (Hanschmidt et al., 2016). In addition, women and couples who are seeking a LTOP often face conflicting social norms. First, the loss of an unborn child, in contrast to the death of an older child, is a socially less recognized death. This means that for some attachment is formative and, most often for outsiders, the unborn child is not yet considered to be part of the family structure and history. Prospective parents often receive reactions such as "you are still young, you will have more children." As a result, they can experience "disenfranchised grief" and feel socially and emotionally isolated (Abraham & Hendriks, 2017; Lafarge et al., 2014). Second, parents (to be) are expected to accept differences in human nature and (physical or mental) capacity of their child, but societies' (social, financial, or emotional) solidarity does not always include those with disabilities. Research has shown that such anticipation of reduced opportunities in society may have an impact on the decision of prospective parents (M. J. Hendriks et al., 2017). Third, LTOP is associated with an action taken by women or couples who do not want a child at that given time, a perspective that opposes the experiences of those with desired and planned pregnancies (McCoyd, 2009). Therefore, how best to support prospective parents is of main importance to perinatal HCPs working in the field (Jones et al., 2017; Lafarge et al., 2014; Lou et al., 2017).

This article offers an insight into the practice of LTOP at ≥20 weeks and the views of parents and the involved perinatal HCPs. It offers an account of the doubts, uncertainties, possibilities, and prospects that parents face after discovering a fetal anomaly in late pregnancy in Switzerland. In this paper, we refer to prospective parents, parents to be, and grieving parents as this is the way how our participants defined themselves.

Materials and methods

Study design, setting, and participants

In our Swiss Neonatal End-of-Life Study (part of the National Research Program [NRP67] "End of life"), a qualitative research design was used to explore and describe the experiences of 20 parents who have lost their child <28 weeks of gestation, irrespective of the reasons that led to its death. For this article we only focus on those five parents who explicitly chose a LTOP at ≥20 weeks of gestation. Their narrative accounts focus on the decision to discontinue a pregnancy and, specifically, the decision-making process. In addition, we sought to compliment the accounts of parents with the views of perinatal HCPs. This was done to gain insight into the professionals' experiences of guiding parents through this difficult time.

The study was conducted in a tertiary perinatal center of a Swiss university hospital. For data collection, we applied the technique of criterion-based, purposive sampling, in that we searched for parents who had experienced the loss of their child in the respective perinatal center one or more years before the onset of our study. A total of 42 eligible parents received a letter from their former physician soliciting their participation in the study, written in two languages (German and English). Due to ethical considerations, we refrained from calling parents and sent a reminder by mail instead. Twenty parents (seven couples, one father, and five mothers) agreed to participate in our Swiss Neonatal End-of-Life project, out of which five parents (two mothers, one father, and one couple) experienced a LTOP. In addition, five perinatal HCPs (i.e., midwife, nurse, obstetrician, neonatologist, and clinical director) participated in the study. One representative of each healthcare discipline relevant to perinatal end-of-life decision-making was purposefully contacted for participation. Interviews with the HCPs were conducted after the interviews with the parents had been completed. The size of the parental sample was largely determined by the availability of respondents and resources to complete the study. Nonetheless, in the last few interviews, significant repetition of themes occurred, suggesting ample sampling and data saturation.

Data collection

To secure a sensitive research approach and to minimize the risk of re-traumatization, we prepared our data collection with participatory observations in the perinatal center. There we gained first insights concerning infrastructures, spatial design, technical environment, daily routines, movement of people etc. Several informal interviews with staff members (e.g., music therapist, spiritual caregiver, nurses) were conducted. Both researchers were present at all encounters during participant observation and during the formal interviews with parents and HCPs. The researchers' scientific background as medical anthropologists was introduced to all participants. Our research affiliation to the hospital was also recognized, while highlighting that we were a) not involved in the medical care of prospective parents and their (unborn) children, and b) obliged to strict confidentiality. The interviews were conducted in a place selected by the participants (i.e., at their home, the working place of the participants or the researchers, or at the university hospital) and audio recorded. Parental interviews were arranged with two mothers, one father, and one couple wished to be interviewed together. The interviews started with the invitation to tell the whole story about their child without interruptions from the researchers' side. After this major narrative component, the researchers continued with a semi-structured part containing narration-immanent and -exmanent questions to clarify and deepen specific themes. The exmanent interview questions focused particularly on communication with HCPs, end-of-life decisions and parents' wishes and preferences (See Manya J Hendriks & Abraham, 2017). Interviews lasted between 60 and 160 min with an average of 97 min. Interviews with perinatal HCPs were semi-structured and took place after the completion of data collection with the parents. The interview guide contained two parts. In the first part, researchers presented preliminary results of the parental interviews and asked HCPs to comment them. The second part was structured by questions on their experiences with decision-making and offering support to parents experiencing the end-of-life of their children. Interviews lasted between 54 and 78 min with an average of 65 min.

Ethical approval

The Ethics Committee of the Canton of Zürich assigned the study a declaration of no objection (Nr. 64-2015). Particular attention was paid to recruitment (formulations and timing), the psychological harm the interview might cause, and verbal and nonverbal communication during the interview (Rosenblatt, 1995). Before the interviews, participants received written and oral information about the study. They were ensured anonymity and provided informed consent. During the interviews, we also conducted "process consenting"; that is, regularly examining the participants' willingness to proceed with the interview. Even though most parents were emotional, none decided to end the interview, and all expressed their gratitude for having the opportunity to tell their story. After the interview, all participants received contact information for psychological support in case needed.

Analysis

Data analysis followed the principles of qualitative content analysis as developed by Kuckartz (2014). It is based upon the following central points of hermeneutical analysis: (1) consideration of the conditions under which data has been collected, (2) applying the hermeneutical cycle (i.e., considering and combining scientific preconceptions and comprehensive ability in text analysis), (3) awareness toward hermeneutical differences, (4) aspiring appropriateness and accuracy in textual understanding (Kuckartz, 2014). Qualitative content analysis applies a deductive–inductive procedure, considering previously defined research questions and reviewed literature, but allowing categories to emerge out of the data. Its characteristics lay in the centrality of categories for analysis, the systematic procedure with a predefined control system for the single analytical steps, the classification and categorization of the entire data material, techniques applied for the construction of empirical categories, hermeneutically inspired reflections, and the acknowledgement of quality criteria such as intersubjective confirmability between researchers (Kuckartz, 2014, p. 39).

Interviews were transcribed verbatim. First, an initial coding scheme was developed based on our research aim, interview guide, reviewed literature, and field notes from the perinatal center. Second, four transcripts were independently coded by both authors to achieve congruent coding practice using a qualitative data analysis software (i.e., MAXQDA version 12). Third, the coding scheme was refined with codes that emerged from the collected data. The scheme comprised a chronologic axis (i.e., pregnancy, birth, liminal phase, end-of-life, dying, and death) and a thematic axis (i.e., experience, values and attitudes, support, and communication). Fourth, all transcripts

Table 1. Characteristics of participants.

Participants				Cases					
	Sex	Pseudonym	Mother tongue	Sex	Gestational age	Indication for LTOP	Treatment	Measures	Time of death
1	F	Mrs. Willows	Swiss German	M	25 0/7 – 6/7	Autosomal recessive polycystic kidney disease	Mifegyne	Caesarean section and palliative care	1 h
2	M	Mr. Adair	Swiss German	M	24 0/7 – 6/7	Trisomy 21	Mifegyne	–	20 min
3	F	Mrs. Rose	German	M	23 0/7 – 6/7	Ventriculomegaly and agenesis of corpus callosum	Mifegyne	–	45 min
4	M F	Mr. & Mrs. Blum	German	M	24 0/7 – 6/7	Triploidy	Mifegyne	–	35 min

were randomly divided between the two researchers and coded alongside the coding scheme. Codes were summarized in a descriptive manner, whereas interpretative notes were formulated in memos. All codes, summaries and memos were cross-checked and complemented by the other researcher. Discrepancies were resolved through repeated discussion. Finally, the codes were systematized and categorized. During analysis careful attention was paid to the fundamental difference but also the manifold similarities between the experience of a LTOP and the unintended death of an extremely preterm-born child, yet without conducting an a-priori separation of these cases. Based on this overall analysis which we described in two articles (Hendriks & Abraham, 2017; Abraham & Hendriks, 2017), the following results apply to the five interviews on LTOP only.

Results

One to two years had elapsed between the time of the pregnancy loss and the interview (Table 1). The interviews illustrated decisional support, the experience of time, continuity of care, the role of midwives, and bereavement care. All names presented are pseudonyms.

Decisional support

Overall, participants raised the topic of decisional support. In the first narrative, Mrs. Willows who ended her pregnancy in the 23rd gestational week, shared her story and explained that at the beginning she felt alone when trying to make the right decision for her unborn child, herself, and her family. Mrs. Willows was concerned about whether it would be the right choice from a philosophical perspective or whether it would be selfish to choose a LTOP.

> I needed a spiritual caregiver, an ethicist, a philosopher, just somebody to talk to about what is right. How should I do this the right way? I wanted to do the right thing, but I had nobody to talk to. During the process of course my husband had an opinion and attitude. For him it was clearer: he would terminate the pregnancy. But he did not want to put pressure on me, so he left the decision up to me. […] All I wanted to do was the right thing. – *Mrs Willows*

After sharing this struggle with her obstetrician and reviewing all the medical data, Mrs. Willows felt supported after receiving advice. According to Mrs. Willows, her obstetrician supported her by stating that; "If she would have been her sister-in-law, she would have recommended to discontinue the pregnancy".

In the case of Mr. Adair, he and his partner also sought decisional support to share their reflections without any judgment – they did not want to be the only ones to carry the weight of the decision. The results of the many tests were discussed with their gynecologist, but it was reiterated that the final decision was theirs to take. Finally, the decision to terminate Mrs. Adair's pregnancy, in the 24th gestational week, was based on their shared reflections with her parents.

All HCPs further mentioned the difficulty of supporting the decision-making of the pregnant woman and her partner. These decisions need to balance the risks for the unborn child and the mother (to be), in which obstetricians main aim is to try to do their best to support the mother (to be) and keep in mind her needs and preferences. Due to the difficult nature of LTOP decisions, HCPs were clear that the process and evaluation of such a decision together with the woman was the most important aspect of counseling.

Experience of time

The narrative of Mrs. Rose illustrated not only the complexity of coming to a decision but also the time pressure. Within a timeframe of 10 days, the prospective parents learned about all the medical facts concerning their unborn child. Once they received the final diagnosis after an MRI, Mrs. Rose explained that

she and her husband had only 48 h to discuss amongst each other whether they would terminate the pregnancy. They were informed that a LTOP by induction of labor could only be conducted before the limit of viability.

> You don't want that as parents, you know then, then they are viable, and then it's - that's murder. Well, in my eyes at least, so I believe that. I found it really difficult so close at the limit; if it was maybe a week or two weeks earlier, then … I would have always had problems with it, but maybe it would have been a bit better. So it was really pushing against the limit now, that it would have been viable. And that does cause problems. – *Mrs. Rose*

Mrs. Rose explained how horrible and awful these 48 h were to think about what they were going to do. Ultimately, Mrs. Rose said that they decided to terminate the pregnancy.

Time constraint was also described by Mr. and Mrs. Blum who were overwhelmed by the entire decision-making process. They had no time to prepare themselves "with the message that something was not right on Friday, the confirmed test results by Wednesday and a decision needed by Sunday". While their private physician contacted the urban university hospital to make sure a LTOP was still legally permissible, the couple had to make their decision. Since Mrs. Blum was in her 24th week of pregnancy, the couple was told it was crucial to decide as quickly as possible. Their decision-making was contingent on whether they wanted to carry out the pregnancy or not; either the fetus would die in-utero, during an induced premature delivery, or at birth at term. The couple explained that continuing the pregnancy felt like waiting for the child's death. The couple also considered their decision to be partly self-protection, to avoid prolonging their suffering.

The obstetrician further mentioned the difficulty of counseling women and couples in these time sensitive situations. With increasing gestational age and moving beyond the limit viability, feticide might remain the only option when a woman would not be physically or mentally able to continue her pregnancy to term. The obstetrician and midwife explained that feticide was considered as highly challenging. According to the clinical director, counseling prospective parents in these situations require a high level of responsibility, team involvement and agreement, and a case-by-case in-depth ethical and legal reflection. The most important thing, according to another obstetric HCPs, was to evaluate these "delicate decisions" really well beforehand.

> Then somehow feticide has to be supported by the team. We always have midwives and nurses involved, to make it clear to all those professions involved that there is no hidden agenda, instead we are fighting for a real decision, and with the question, is this very late termination in conformity with the law? Can we as a clinic support something like this, […] but in the end, and that is the most important thing, is it the right decision from the woman's point of view, because even in these situations there is no good decision, it is only the least bad one. So to actively abort the child and kill it while it is still in the womb, a woman needs a lot of stability in the long term to cope with this. – *Obstetrician*

Continuity of care

Most participants described positive alongside negative experiences regarding the continuity of care and communication with or between HCPs. Mr. Adair described that in coming to a decision, he and his partner felt that no one was guiding them through the initial period of prenatal and genetic testing.

> We received the results by telephone. It was very factual and then there was a pause, ok and what now? We did not know what to do next and where and to whom we should go. That was the main issue where, retrospectively, I say there was no common thread or person in charge. – *Mr. Adair*

They described that different care providers gave them different information, resulting in not knowing what to do next and where and to whom to go. Their main difficulty was that there was "no common thread or person in charge."

Mrs. Rose described that both the obstetrician and midwife had informed her and her husband about the dying process (i.e., what could happen during the LTOP and the possibility of a live birth) in a calm manner. However, there were also moments where the communication between perinatal HCPs was lacking. Mrs. Rose described the difficult moment of waiting for a HCP for two hours, while sitting in front of the "pillbox" that would induce her labor. In addition, a few days after Mrs. Rose was released from the hospital she was mistakenly called with the request "to come to the newborn screening". This left Mrs. Rose with the task to explain her situation, which made her feel very distraught. Similarly, Mr. and Mrs. Blum who were well-informed by an obstetrician and midwife about the whole medical process, found that their anesthesiologist had not been properly informed. When Mr. and Mrs. Blum came into the hospital for the LTOP procedure, their anesthesiologist thought they were preparing for a regular birth with a desired

epidural. In fact, the obstetrician recognized that in the past the information flow did not move properly between HCPs. This resulted into horrible mishaps where one would "go into the room and find a crying woman with no idea why". According to the obstetrician, with the help of a new IT system in place such information mismatches should be minimized. In addition, all HCPs agreed that midwives were often the HCPs who served continuity in the care during and after the LTOP.

> I'm also a very big fan of a contact person for the medical and nursing care, who ultimately accompanies the parents through the whole process as a contact person. I find that very, very important. For example, in the delivery room, the midwives are in charge. – *Obstetrician*

Role of midwives

Participants mentioned that whereas the obstetrician offered support during the decision-making process, midwives were the main care providers once the decision had been made by the couple. Overall, midwives helped expectant parents cope with their situation and provided advice and support for preparing for this difficult moment.

> We have this consultation at admission, we ask the parents, if it would come to that, what they would like to do: would they like to see the child, how should we dress the child, and how they would wish to proceed. We actually discuss everything and give enough space. […] But what we arrange is that when a midwife accompanies a woman, knowing that the child could be born dead, she looks after that woman and no one else. […] so that you can also give the full attention to this woman. – *Midwife*

On the one hand, parents were informed how the dying process would proceed medically/technically and physically called an "intake conversation". On the other hand, parents were encouraged to bring along something, which linked them to their unborn child, which they could leave with their child or keep as a memory. The interviewed midwife explained how the delivery ward uses a special concept for anticipatory grieving. Every new employee receives classes on how they should behave toward the parents and specifically the mother (to be).

All participants considered that the midwives who supported them were very professional and noticed that they had a "careful and gentle" routine in how they proceeded with LTOPs. In addition, prospective parents did not feel any difference in quality of care between the different midwives. All of them were considered empathic, while also being honest and treating mothers (to be) "normally and not oversensitively".

> Yes, this empathy that these women, or I can only say it about me now, that they had towards me, is really, phew! So hats off to those for their work! Also, I had one who was on a late shift, and I asked her whether they had many cases like this in the university hospital, and then she said, yes, it just happens more often in the university hospital. But they are also very closely supervised and so on. And she said that such cases are then also worked through again. I said, hey phew! I don't know if I could do that. – *Mrs. Blum*

Prospective parents further mentioned how midwives knew the appropriate moment to leave the family alone. This was confirmed by a midwife, who mentioned the difficult balance of providing supportive care from a distance that respects the intimate nature of the situation without imposing some preferred actions or rituals. For example, many parents were happy that midwives took pictures of their children. However, not every couple felt the same. Mr. Adair and his partner did not want any pictures to be taken during the time the baby was still alive, since they did not want to disrupt the time they had together. Their preference was simply different. Indeed, all HCPs mentioned that especially in the process of dying it is very important to individualize care and to offer the best possible support for the prospective parents in question.

Bereavement care

Different types of bereavement services were described. All grieving parents described the opportunity to say their goodbyes in "the room of silence", a place next to the delivery room especially designed for seeing and holding ones deceased child. Grieving parents also had an individual room where, if they wanted, could bring their child. According to all perinatal HCPs, no standardized bereavement services are offered to families with a LTOP after leaving the hospital.

> It always depends on what the cause is. For example, if we know that the child has a malformation and we do not yet know what the child really had, […] then we will see if the parents agree to an autopsy, and wait for the autopsy results and the discussion with the pediatric pathologists and the geneticists, and then call the woman back in specifically to discuss the risk of recurrence and things like that. […], we have a follow-up six weeks after each birth anyway, then exactly follow-up is used for the conversation. […] Some women want that, the women want a

> debriefing again with us, about this birth. But there are many doctors [regional OB-GYN] who do a super job, and it makes no sense to send someone who is well embedded there and has been cared for, for many years to a university clinic, where there is perhaps some doctor who doesn't know the case at all. So it really depends on the situation. – *Clinical director*

Depending on the case, some women and/or couples have a consultation with the obstetrician and/or pathologist about the cause of death, meet with their gynecologist for aftercare, or families can arrange a midwife at home who is specialized in perinatal loss. The midwife mentioned she had called some grieving parents after 6–8 weeks but due to negative response, they had stopped the initiative.

Grieving parents described different preferences and needs for bereavement care. For example, Mr. Adair and Mr. and Mrs. Bloom searched for further bereavement care and found support from a midwife at home with expertise in perinatal loss. In the case of Mrs. Willows, she and her husband did not talk about their loss for over a year and she had not confided in other friends. Although she had wished further care from the hospital, she did not proactively request further bereavement services.

> I was offered a conversation after the whole thing. But did not go. No. I think it was still a bit too early. And it was in writing, I have to say, I would definitely do that by phone, because you are all over the place in the beginning anyway - because you react negatively at first; oh no, I don't want to deal with it again. At least with me it was like that. […] There, I really have to say, it needs someone who then actively approaches someone, really calls them on the phone and says, "Come and talk to me." - It is also very nice someone showing such interest in this bad experience. But of course it took time to find the strength to do this. I think it takes at least six months, which must pass. And then it would be better to call this person and tell them to come, not to send a written invitation. So I did not react to it. And now it's too far away, I wouldn't do it now. – *Mrs. Willows*

Only after repeated suggestions and phone calls from an organization on perinatal loss, Mrs. Willows participated in a drawing therapy/class and a parent support group for mothers who lost a baby. Similarly, Mrs. Rose had not mentioned anything about her LTOP to her close friends and had not proactively searched for bereavement services. She described how she received valuable support from her husband and parents. But her older son, she said, ultimately saved her. She had to go on for him, explain to him what had happened, and as his life continued she was able to do so as well.

Discussion

Overall, our findings illustrate how prospective parents with a diagnosed fetal anomaly in the second trimester experience the process of decision-making, care, and bereavement support in a Swiss perinatal center. These narratives encompass several themes such as the difficult nature of decision-making in the context of LTOP, the perceived pressure of time, fragmented healthcare support during prenatal diagnosis, and the lack of standardized bereavement care.

Our findings illustrate that decisions about LTOPs at $\geq$20 weeks after a prenatal diagnosis were often framed in the context of having to make one's own decision that respected the individual autonomous choices of mothers (to be) and/or couples. However, even though the ultimate decision was based on the women or couples' judgments, they often desired professional or philosophical support and/or reassurance that they were doing the right thing. This shows the difficult balancing act of obstetric HCPs who ought to provide non-directive counseling to enable informed decision-making, which includes presenting all alternative measures (McCullough et al., 2019).

As shown in the narratives, obstetric HCPs sometimes struggle with this balancing act. This opposition has also been shown in other studies, in which virtues like trust, compassion and beneficence are difficult to reconcile with non-directiveness and parental autonomy in decision-making (Koponen et al., 2013; Ville & Lafarge, 2020). This difficulty might be the result of a *rational* understanding of autonomy that fails to consider the relational and emotional dynamics of prenatal decision-making. Although medical practice has recognized the importance of emotions in communication training and in teaching HCPs how to manage the emotional burden of their work (Bry et al., 2016; Cricco-Lizza, 2014), incorporating emotions into the decision-making process is less common (Ferrer et al., 2015). In fact, evidence has shown that depending on the circumstances emotions can facilitate or hinder decision-making (Ferrer & Ellis, 2019). In the context of a prenatal diagnosis, some studies have showed that emotions can influence the decision-making process (Gengler, 2020; St-Jacques et al., 2008). When emotions are mobilized in the decision-making process parents can make decisions more confidently. In addition, emotions can serve as a protective measure for interpersonal relationships

between parents and HCPs (Gengler, 2020). Not surprisingly, women have called for more and better emotional and psychological support during and after their decisions (Blakeley et al., 2019).

Future work should further investigate the dynamic and influence of emotions on prenatal decision-making and incorporate it into clinical practice (Ferrer & Ellis, 2019; Gengler, 2020). In addition, such future work should take into consideration the complexity of such an endeavor. HCPs cannot "manage" or "control" parents' emotions and yet HCPs should find ways to safeguard that emotions are part of the decision for parents to come to terms with their decision. The failure to consider relational dynamics might be further explained by the tension between the Swiss law and clinical practice. Although the legal responsibility of LTOP decisions beyond 12 weeks lies with the attending HCPs (in his/her judgment of a medical or socio-medical indication), this alone is not sufficient. The free decision of the woman is ultimately decisive (NEK, 2018; Schweizer Strafgesetzbuch, 2011). In turn, this might leave some women alone in this difficult decision-making process. However, in light of ethical standards of shared decision-making, it is recommended that the attending physician and midwife are involved in the decisional process and foster a detailed discussion that is rooted in the parents' values and needs. In fact, recent studies have shown a positive effect of shared decision-making on psychological outcomes in LTOP (Kerns et al., 2018). Further, our findings on the need for more decisional support should not be confused with a lack of "decisional certainty" from prospective parents. Instead, the need for decisional support may be a mere expression of the loneliness experienced by the one who must take the decision. In fact, despite the large and long-lasting psychological consequences of LTOP for fetal anomaly, only <3% of women mention feelings of strong regret (Korenromp et al., 2009).

Although it is widely recognized that prospective parents in LTOP situations need time to understand their situation, obtain information, and reflect on the available options to make an informed decision (Lou et al., 2017), our findings show that some experience time pressure. This unduly complicates an already complicated decision-making process. One explanation could be the Swiss medico-legal context surrounding LTOPs at the limit of viability. One study found that the clinical practice of HCPs illustrate that LTOPs are judged more acceptable at earlier gestational ages when extrauterine life is not possible (F. Berger et al., 2020). This stands in contrast with France where most LTOPs performed in second and third trimester were followed by feticide (Maurice et al., 2019). Thus, the Swiss medico-legal context potentially brings into play significant time pressure on prospective parents in prenatal counseling and decision-making. Nonetheless, and more importantly, Swiss law does *not* define any gestational age limits for LTOP (Schweizer Strafgesetzbuch, 2011).

It is, therefore, ethically questionable that the unease of HCPs or institutions regarding feticide seems to place prospective parents under such time pressure. Apart from literature on the moral and ethical nature of abortion and feticide, so far, little information exists about the experiences of parents and HCPs with feticide (Graham et al., 2009; Leichtentritt & Mahat-Shamir, 2017; Power et al., 2020). Fay et al. (2016) have shown that feticide for HCPs is considered emotionally and technically difficult, yet also a necessary part of caregivers' tasks. Further investigation into the necessary support and guidance in self-management of distress is needed to ensure professionalism in the field. Considering the weight and impact that LTOP decisions have on prospective parents, it is essential that decisions are recognized as the major life crises that they are that, as a result, require more time and space for support from the healthcare team. However, time pressure and decisional loneliness might also be the result of fragmentation of care and the delay that decentralized care can cause, which might lead to situations where little time is left for a well-informed decisional process (Flaig et al., 2019).

Prospective parents described how different HCPs were responsible for the care in the various phases during prenatal screening/diagnostics and after the decision to terminate. As a result, this was not sufficiently coordinated. Other studies also showed how fragmented care can negatively impact prospective parents. In fact, they showed a lack of interdisciplinary collaboration between different disciplines and between different facilities (i.e., regional centers versus centers that perform abortions) in Switzerland (NEK, 2018; Rey & Seidenberg, 2010). Therefore, it is essential that counseling is centralized and that collaboration exists between the different perinatal specialists (i.e., the genetic counselor, obstetrician, midwife, and –depending on the fetal diagnosis– a neonatologist, social worker, or palliative care provider) to provide timely and professional support to prospective parents.

A more structured implementation of some of the principles of perinatal palliative care might help address

this limitation and further complement and integrate the supportive actions of perinatal specialists (Denney-Koelsch & Côté-Arsenault, 2020; Flaig et al., 2019). Although there is some debate about the role of perinatal palliative care in situations where women or couples consider terminating their pregnancy (Lefkowits & Solomon, 2016; Rusalen et al., 2019), it goes without saying that involved families should receive well-established longitudinal care (including bereavement support) and time to make an informed decision. Furthermore, within this framework, prospective parents are well-support and empowered on how they can guide their living and, eventually, dying child for the time he or she has left. Professional organizations increasingly recognize the perinatal palliative care model and the value of a multidisciplinary team encompassing perinatal specialists. Indeed, one of the principles of perinatal palliative care is to bring together the collective wisdom of all relevant stakeholders and support collaboration within existing structures to provide consistent support and good access to care (Denney-Koelsch & Côté-Arsenault, 2020).

Our findings further identify the lack of follow-up bereavement care for LTOP. Even though the provision of care on anticipatory grieving from midwives played a key role in supporting prospective parents, standardized aftercare was lacking. After a LTOP, follow-up by providers can be essential and serve as a foothold during hard times (Denney-Koelsch & Côté-Arsenault, 2020). Findings on grieving parents' needs and preferences for support in aftercare of LTOP remain limited, but some studies show that there is a need for continued follow-up care into bereavement (Hanschmidt et al., 2018; Lafarge et al., 2014; Ramdaney et al., 2015). Moreover, our findings illustrate the complexity with standardizing bereavement care. This has been confirmed by other studies (Wiener et al., 2018). Grief is a highly individualized process, with some parents appreciating, for example, a phone call after some weeks, while others consider it an additional burden. Institutional policies should allow for a personalized approach to bereavement interventions based on the needs of bereaved parents and the resources of the center (Wiener et al., 2018). More focus should be given on a standardized support from (outpatient) midwives, nurses, or psychologists specialized in perinatal death. In addition, follow-up bereavement support services are becoming more available within perinatal palliative care (Denney-Koelsch & Côté-Arsenault, 2020). It should be further explored whether such existing care pathways can help perinatal specialists in offering aftercare to families who have experienced an LTOP, while recognizing their particular needs and the distinctive nature of bereavement in LTOP (Lafarge et al., 2014).

There are several limitations to this study. Despite the added richness of using a narrative approach to understand LTOPs, our qualitative design imposed a limited sample size. Moreover, the illustrated narratives stem from a single perinatal center. Since we interviewed participants who were willing to volunteer for our empirical study, it can be speculated that their experiences have been especially good or bad. Although their experiences were traumatic and not easily forgotten, participants recalled events that occurred in the past and thus reconstructed their LTOP experience with a distance of at least one year. Consequently, the retrospective nature of this study could have led participants to respond with socially desirable answers or to remember some experiences inaccurately. Even though the interviews' content is rich, the sample size is very small. Further studies should deepen the described insights and narrow the research design to parents who have experienced an LTOP.

Our study shows that prospective parents who are faced with making a prenatal decision on whether to (dis)continue their pregnancy need more decisional support. Moreover, prospective parents should be granted with the time and support needed to make such a major decision. Although it is well-established that the woman is central to decision-making in female reproductive health, it should not be forgotten that perinatal specialists play an important role in empowering women and offering professional support. Moreover, ensuring an integrated perinatal palliative care in the existing structures of the perinatal center could help overcome the limitations of care expressed by prospective parents. Specifically, it could help address the loneliness of the decision, reduce the fragmentation of care, and offer bereavement services for the months and/or years following the child's death. Moreover, development of evidence-based models for aftercare should be further researched and established, which include the needs of grieving parents and allows a flexible timeframe for uptake.

Disclosure statement

The authors declare that there is no conflict of interest.

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Data availability statement

The analysis of the study is available from the corresponding author upon request.

Notes

1. Of note, terminology around abortion and LTOP can be contradictory. To date, there is no generally accepted definition of LTOP, which ranges from ≥12 to ≥24 weeks of gestation. For the sake of clarity, in this article we will focus on LTOPs carried out around the limit of viability at ≥20 weeks of gestation.
2. The procedure of feticide entails an intracardial injection of potassium or the injection of digoxin into the umbilical cord or amniotic fluid by an obstetrician specialized in prenatal medicine. In addition, aesthetic analgesics and/or sedatives are sometimes administered to the fetus via the pregnant woman (NEK, 2018; Tanner, 2011).

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References

Abraham, A., & Hendriks, M. J. (2017). "You can only give warmth to your baby when it's too late": Parents' bonding with their extremely preterm and dying child." *Qualitative Health Research*, *27*(14), 2100–2115. https://doi.org/10.1177/1049732317721476

Berger, F., Bucher, H. U., Fauchère, J.-C., Schulzke, S., & Berger, T. M. (2020). Overlapping borders: Limit of viability and late terminations of pregnancy–A retrospective multicentre observational study. *Swiss Medical Weekly*, *150*, w20186. https://doi.org/10.4414/smw.2020.20186

Berger, T. M., Bernet, V., El Alama, S., Fauchere, J. C., Hosli, I., Irion, O., Kind, C., Latal, B., Nelle, M., Pfister, R. E., Surbek, D., Truttmann, A. C., Wisser, J., & Zimmermann, R. (2011). Perinatal care at the limit of viability between 22 and 26 completed weeks of gestation in Switzerland. 2011 revision of the Swiss recommendations. *Swiss Medical Weekly*, *141*, w13280. https://doi.org/10.4414/smw.2011.13280

BFS (2019). *Anzahl Schwangerschaftsabbrüche nach Schwangerschaftswoche, nach Wohnsitz* (No. je-d-14.03.07.02.24). Bundesamt für Gesundheit. https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit.assetdetail.5328568.html

Blakeley, C., Smith, D. M., Johnstone, E. D., & Wittkowski, A. (2019). Women's lived experiences of a prenatal diagnosis of fetal growth restriction at the limits of viability: An interpretative phenomenological study. *Midwifery*, *76*, 110–117. https://doi.org/10.1016/j.midw.2019.05.015

Bry, K., Bry, M., Hentz, E., Karlsson, H. L., Kyllonen, H., Lundkvist, M., & Wigert, H. (2016). Communication skills training enhances nurses' ability to respond with empathy to parents' emotions in a neonatal intensive care unit. *Acta Paediatrica (Oslo, Norway: 1992)*, *105*(4), 397–406. https://doi.org/10.1111/apa.13295

Cricco-Lizza, R. (2014). The need to nurse the nurse: Emotional labor in neonatal intensive care. *Qualitative Health Research*, *24*(5), 615–628. https://doi.org/10.1177/1049732314528810

Denney-Koelsch, E. M., & Côté-Arsenault, D. (2020). *Perinatal palliative care: A clinical guide*. Springer.

DiMiceli-Zsigmond, M., Williams, A. K., & Richardson, M. G. (2015). Expecting the unexpected: Perspectives on stillbirth and late termination of pregnancy for fetal anomalies. *Anesthesia and Analgesia*, *121*(2), 457–464. https://doi.org/10.1213/ANE.0000000000000785

Fay, V., Thomas, S., & Slade, P. (2016). Maternal-fetal medicine specialists' experiences of conducting feticide as part of termination of pregnancy: A qualitative study. *Prenatal Diagnosis*, *36*(1), 92–99. https://doi.org/10.1002/pd.4720

Ferrer, R. A., & Ellis, E. M. (2019). Moving beyond categorization to understand affective influences on real world health decisions. *Social and Personality Psychology Compass*, *13*(11), e12502. https://doi.org/10.1111/spc3.12502

Ferrer, R., Klein, W., Lerner, J., Reyna, V., & Keltner, D. (2015). Emotions and health decision-making: Extending the appraisal tendency framework to improve health and healthcare. In C. A. Roberto & I. Kawachi (Eds.), *Behavioral economics and public health* (pp. 101–132). Oxford University Press.

Flaig, F., Lotz, J. D., Knochel, K., Borasio, G. D., Führer, M., & Hein, K. (2019). Perinatal palliative care: A qualitative study evaluating the perspectives of pregnancy counselors. *Palliative Medicine*, *33*(6), 704–711. https://doi.org/10.1177/0269216319834225

Fleming, V., Frith, L., Luyben, A., & Ramsayer, B. (2018). Conscientious objection to participation in abortion by midwives and nurses: A systematic review of reasons. *BMC Medical Ethics*, *19*(1), 31. https://doi.org/10.1186/s12910-018-0268-3

Gengler, A. M. (2020). Emotions and medical decision-making. *Social Psychology Quarterly*, *83*(2), 174–194. https://doi.org/10.1177/0190272519876937

Graham, R., Mason, K., Rankin, J., & Robson, S. (2009). The role of feticide in the context of late termination of pregnancy: A qualitative study of health professionals' and parents' views. *Prenatal Diagnosis*, *29*(9), 875–881. https://doi.org/10.1002/pd.2297

Hanschmidt, F., Hoffmann, R., Klingner, J., Kersting, A., & Stepan, H. (2018). Help-seeking following termination of pregnancy after diagnosis of fetal anomaly: Women's Intentions and Experiences 1 to 7 Years after the Event.

Geburtshilfe Und Frauenheilkunde, *78*(2), 160–166. https://doi.org/10.1055/s-0044-100380

Hanschmidt, F., Linde, K., Hilbert, A., Riedel- Heller, S. G., & Kersting, A. (2016). Abortion stigma: A systematic review. *Perspectives on Sexual and Reproductive Health*, *48*(4), 169–177. https://doi.org/10.1363/48e8516

Hendriks, M. J., & Abraham, A. (2017). End-of-life decision making for parents of extremely preterm infants. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, *46*(5), 727–736. https://doi.org/10.1016/j.jogn.2017.06.006

Hendriks, M. J., Bucher, H. U., Klein, S. D., Streuli, J. C., Baumann-Holzle, R., & Fauchere, J. C. (2017). Exploring societal solidarity in the context of extreme prematurity. *Swiss Medical Weekly*, *147*, w14418. https://doi.org/smw.2017.14418

Jones, K., Baird, K., & Fenwick, J. (2017). Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy: A qualitative meta-synthesis. *Midwifery*, *50*, 42–54. https://doi.org/10.1016/j.midw.2017.03.014

Kerns, J. L., Mengesha, B., McNamara, B. C., Cassidy, A., Pearlson, G., & Kuppermann, M. (2018). Effect of counseling quality on anxiety, grief, and coping after second-trimester abortion for pregnancy complications. *Contraception*, *97*(6), 520–523. https://doi.org/10.1016/j.contraception.2018.02.007

Koponen, K., Laaksonen, K., Vehkakoski, T., & Vehmas, S. (2013). Parental and professional agency in terminations for fetal anomalies: Analysis of Finnish women's accounts. *Scandinavian Journal of Disability Research*, *15*(1), 33–44. https://doi.org/10.1080/15017419.2012.660704

Korenromp, M. J., Page-Christiaens, G. C., van den Bout, J., Mulder, E. J., & Visser, G. H. (2009). Adjustment to termination of pregnancy for fetal anomaly: A longitudinal study in women at 4, 8, and 16 months. *American Journal of Obstetrics & Gynecology*, *201*(2), 160.e1–160.e7. https://doi.org/10.1016/j.ajog.2009.04.007

Kuckartz, U. (2014). Qualitative inhaltsanalyse: Methoden, praxis, computerunterstützung. Beltz Juventa.

Lafarge, C., Mitchell, K., & Fox, P. (2014). Termination of pregnancy for fetal abnormality: A meta-ethnography of women's experiences. *Reproductive Health Matters*, *22*(44), 191–201. https://doi.org/10.1016/S0968-8080(14)44799-2

Lefkowits, C., & Solomon, C. (2016). Palliative care in obstetrics and gynecology. *Obstetrics and Gynecology*, *128*(6), 1403–1420. https://doi.org/10.1097/AOG.0000000000001739

Leichtentritt, R. D., & Mahat-Shamir, M., (2017). Mothers' continuing bond with the baby: The case of feticide. *Qualitative Health Research*, *27*(5), 665–676. https://doi.org/10.1177/1049732315616626

Lou, S., Jensen, L. G., Petersen, O. B., Vogel, I., Hvidman, L., Møller, A., & Nielsen, C. P. (2017). Parental response to severe or lethal prenatal diagnosis: A systematic review of qualitative studies. *Prenatal Diagnosis*, *37*(8), 731–743. https://doi.org/10.1002/pd.5093

Maurice, P., Letourneau, A., Benachi, A., & Jouannic, J. M. (2019). Feticide in second- and third-trimester termination of pregnancy for fetal anomalies: Results of a national survey. *Prenatal Diagnosis*, *39*(13), 1269–1272. https://doi.org/10.1002/pd.5594

McCoyd, J. L. (2009). Discrepant feeling rules and unscripted emotion work: Women coping with termination for fetal anomaly. *American Journal of Orthopsychiatry*, *79*(4), 441–451. https://doi.org/10.1037/a0010483

McCullough, L. B., Coverdale, J. H., & Chervenak, F. A. (2019). *Professional ethics in obstetrics and gynecology*. Cambridge University Press.

NEK. (2018). *Zur Praxis des Abbruchs im späteren Verlauf der Schwangerschaft – Ethische Erwägungen und Empfehlungen*. N. Ethikkommission. https://www.nek-cne.admin.ch/inhalte/Themen/Stellungnahmen/NEK_Stellungnahme_Abbruch_im_spaeteren_Verlauf_der_Schwangerschaft_D.pdf

Oelhafen, S., Monteverde, S., & Cignacco, E. (2019). Exploring moral problems and moral competences in midwifery: A qualitative study. *Nursing Ethics*, *26*(5), 1373–1386. https://doi.org/10.1177/0969733018761174

Power, S., Meaney, S., & O'Donoghue, K. (2020). Fetal Medicine Specialists' experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: A qualitative study. *BJOG*, *128*(7), 676– 684. https://doi.org/10.1111/1471-0528.16502

Ramdaney, A., Hashmi, S. S., Monga, M., Carter, R., & Czerwinski, J. (2015). Support desired by women following termination of pregnancy for a fetal anomaly. *Journal of Genetic Counseling*, *24*(6), 952–960. https://doi.org/10.1007/s10897-015-9832-x

Rey, A., & Seidenberg, A. (2010). Schwangerschaftsabbruch: Die Praxis der Spitäler und Kliniken in der Schweiz. *Schweizerische Ärztezeitung*, *91*(13/14), 551–554. https://saez.ch/journalfile/download/article/ezm_saez/fr/bms.2010.15075/a4b6985091d9cd9175c1d6596b5f03c48660dfd2/bms_2010_15075.pdf/rsrc/jf

Rosenblatt, P. C. (1995). Ethics of qualitative interviewing with grieving families. *Death Studies*, *19*(2), 139–155. https://doi.org/10.1080/07481189508252721

Rusalen, F., Cavicchiolo, M. E., Lago, P., Salvadori, S., & Benini, F. (2019). Perinatal palliative care: A dedicated care pathway. *BMJ Supportive Palliative Care*. https://doi.org/10.1136/bmjspcare-2019-001849

Schweizerisches Strafgesetzbuch. (2002). Artikel 119. https://www.gesetze.ch/sr/311.0/311.0_016.htm#13

Singh, S., Remez, L., Sedgh, G., Kwok, L., & Onda, T. (2018). *Abortion worldwide 2017. Uneven progress and unequal access*. G. Institute. https://www.guttmacher.org/report/abortion-worldwide-2017

St-Jacques, S., Grenier, S., Charland, M., Forest, J. C., Rousseau, F., & Légaré, F. (2008). Decisional needs assessment regarding Down syndrome prenatal testing: A systematic review of the perceptions of women, their partners and health professionals. *Prenatal Diagnosis*, *28*(13), 1183–1203. https://doi.org/10.1002/pd.2059

Ville, I., & Lafarge, C. (2020). Frames of decision-making in prenatal consultations in England and France. Towards a sociological, relational, and processual approach to autonomy. *Journal of Evaluation in Clinical Practice*, *26*(2), 474–483. https://doi.org/10.1111/jep.13368

Wiener, L., Rosenberg, A. R., Lichtenthal, W. G., Tager, J., & Weaver, M. S. (2018). Personalized and yet standardized: An informed approach to the integration of bereavement care in pediatric oncology settings. *Palliative & Supportive Care*, *16*(6), 706–711. https://doi.org/10.1017/S1478951517001249